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Population Registries and Other Record Resources for Epidemiologic Cancer Research in the United States and Japan

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On the basis of the author's experience in epidemiologic studies on cancer in both the United States and Japan for the last 15 years, advantages and disadvantages of various record systems that can be utilized for epidemiologic cancer studies in these two countries are compared.

Both countries are equally well provided with vital statistics and census records. Descriptive studies can be conducted without difficulties in both countries. For analytic studies, the Koseki record or family registration system in Japan provides an excellent tool in tracing subjects. However, Japanese record systems have problems as to management of hospital records, preservation of death certificates, etc. On the whole, restrospective cohort studies, particularly studies on patients, are more difficult in Japan than in the United States. There appear to be no material differences between these two countires as to case-control studies.

The present paper deals with population registries and other record resources for epidemiologic cancer research studies in the United States and Japan. During the past 15 years, I worked as a cancer epidemiologist, half of the time in the United States and the other half in Japan. Therefore, I may be in a better position to evaluate and compare the record systems between the two countries. The record systems in each country have both advantages and disadvantages in regard to uses for epidemiologic cancer research studies. Based primarily on my own experience, I wish to compare the record systems between the U.S. and Japan.

As you know, epidemiologic studies are classified into descriptive and analytic studies. Descriptive cancer epidemiology is the study of the distribution of cancer in different subgroups of the population according to sex, age, occupation, religion, etc. and serve to formulate a hypothesis(es) regarding the etiological factor(s) of cancer. For descriptive studies, we utilize, primarily, vital statistics records and census records from central or local governments. Such records may be lacking among developing countries, but are certainly available in both the United States and Japan. I do not see much difference in regard to availability and quality of these records between the two countries.

In order to test the hypothesis, we have to turn to analytic studies. We have to initiate special projects, either case-control or cohort studies. A cohort study consists of two groups of people, those who are exposed to a suspected risk factor and those who are not, who are followed for the sufficient period of time. Cancer mortality or cancer incidence between the exposed and nonexposed groups are then compared. A case-control study consists of cancer patients and their control subjects who are selected and compared with respect to their past exposure to a suspected risk factor(s). With regard to analytic studies, I see a very substantial difference in availability of record systems between the United States and Japan.

One of the analytic studies in which I am involved at present is a follow-up study on Pearl Harbor Naval Shipyard workers who were exposed to asbestos. This is a so-called retrospective cohort approach, in which workers were selected in the distant past and were followed up to the present to assess their risks for the development of cancer — more specificially, a restrospective cohort of approximately 9500 workers who were on the personnel rolls on January 1,

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1950 or were hired subsequently through 1970 was selected and followed up to January 1, 1974.

Tracing of about 9500 workers for more than 20 years is by no means an easy task. After approximately 4000 subjects had been traced by the employee record, the driver's license file and the state income tax return file were used as the major sources of tracing the subjects. These files were computerized so that identification of workers within these record files was done rather easily. In addition, Medicare records, death files, telephone contacts, Polk's city and island directories, telephone directories, Social Security records, and Veterans' Administration records were used for tracing the subjects. According to the latest tabulation, the follow-up rate stands at 92%.

Let's suppose that I intend to conduct a similar study on shipyard workers in Japan. Could I use Japanese records similar to those of Hawaii as follow-up resources? Table 1 illustrates the feasibility for follow-up for each record. As you see, my judgement is that the most of the records as listed, are, on the whole, not available or are not useful for follow-up in Japan. For example, record keeping is rather poor in Japan, and the past employee record may not be as useful as that in the United States. The driver's license record is not much use because only a small fraction of workers at old ages have a driver's license. A computerized income tax return file is not available.

Table 1. Follow-up scheme in Japan.

	Feasibility
Employee record	±
Driver's license	−
Income tax return	−
Medicare	−
Deaths file	±
Telephone contacts	±
Polk's city directories, telephone directories	±
Social security administration	−
Veterans administration	−

On the whole, a retrospective cohort study seems to be more difficult in Japan than in the United states. However, one advantageous record system for the follow-up in Japan is the Koseki record system. Drs. Tokudome and Kuratsune, my former colleagues at the Department of Public Health of Kyushu University, did a retrospective cohort study of workers at a metal refinery to assess their risks for various sites of cancer (*1*). I used to emphasize that we use the Koseki record system for follow-up studies because I was much impressed by the usefulness of that system in Japan. As some of you may recall, we had a symposium on record linkage as related to cancer research, chaired by Dr. Robert Miller, at the 10th International Cancer Congress. I talked about the special features of the Japanese record systems and emphasized the usefulness of the Koseki system for epidemiologic cancer research in Japan (*2*). At any rate, in this study, 2675 workers were successfully traced by the Koseki system for the time period between 1949 and 1971.

Let me explain next the details of the Koseki record system. This is a family registration system. Vital information for each member of the family is recorded on the Koseki or family registry at the municipal office of the Honseki or legal permanent place of residence of the family. The information on the Koseki includes, for each member of the family, the date and place of birth, the date and place of marriage, the date and place of death, and so forth. It also provides a means of identification and follow-up of both blood-tied and marriage-tied relatives. The Koseki records used to be completely open for the public since its setup in 1871. Because of growing concern of privacy protection, certain restrictions were enforced in the past several years. However, as far as epidemiologic cancer research studies are concerned, I believe that investigators can obtain authorization from the administration for medical reasons and can have access to the Koseki record.

The Koseki record is widely used to trace cancer patients after treatments. Survival studies in Japan depend heavily on this system. Cohort studies also utilize the Koseki system. A notable example is that the Radiation Effects Research Foundation (formerly the Atomic Bomb Casuality Commission) has been following, by the Koseki system, approximately 100,000 radiation-exposed and control subjects.

I was interested in the association between gastric ulcer and gastric cancer almost 15 years ago. Some Japanese pathologists at the time claimed that more than 50% of gastric cancers originated from preexisting ulcers in the stomach. In order to assess whether gastric ulcer predisposes to gastric cancer, I followed nearly 2000 gastric ulcer patients for 8-18 years in the Boston area. I concluded from this study that gastric ulcer patients did not have a higher risk for gastric cancer. After this study was completed, I planned to conduct a similar study in Japan. Unfortunately, this type of study, a retrospective cohort study of patients, was practically impossible in Japan. One of the major reasons for this is certain defects of the hospital record system in Japan. This prompted me to conduct a survey of the hospital record system in Japan.

A survey on the management of medical records in Kyushu was completed and some of the results are

presented in Table 2. We sent questionnaires to all hospitals (946 hospitals) in the Kyushu area regarding the management of hospital records. The response rate was 85%. The results were discouraging. Only 27% had a discharge summary. Only 5% had a disease index. Affirmative response on the existence of a medical librarian was 11%; records preserved in the medical record room, 17%, preserved over 15 years, 18%, Honseki recorded, 24%. So, you would understand why a retrospective cohort study of patients is very difficult in Japan. Identification and selection of patients of a particular type of disease in the distant past is very difficult because of deficiencies of the medical record system.

Table 2. Management of hospital records (946 hospitals in Kyushu)

	% Responding yes
Discharge summary	27
Disease index	5
Medical librarian	11
Preserved in the medical record room	17
Preserved over 15 years	18
Honseki recorded	24

In addition to the problems of medical records, poor management of death certificates imposes an additional problem. In the United States, death certificates are preserved in the Department of Health for each state for a long period of time. For example, according to my own experience in Massachusettes, death certificates are kept for an indefinite period of time. In Hawaii, the death certificates are preserved for at least half a century. In contrast, death certificates are kept only 3 years at health centers and only 5 years at the Bureau of Juridicial Affairs in Japan. Thus, causes of deaths cannot be determined if deaths had occurred 5 or more years ago. If the Honseki is known for most of the subjects, death certificates can be located retrospectively for the past 27 years because they are preserved in the Bureau of Juridicial Affairs of the Honseki or permanent legal place of residence of the family for 27 years.

We have completed a follow-up study on leprosy patients in relation to their risks for cancer (*4*). The immunological surveillance system is an important subject in the etiology and treatment of cancer today. Lepromatous leprosy patients are immunologically incompetent, whereas tuberculoid patients are competent. Thus, it is very interesting to ascertain and compare cancer risks among lepromatous and tuberculoid leprosy patients. About 1100 leprosy patients in Hawaii were followed from 1940 to 1970 and their mortaility experience from cancer was determined. The follow-up rate was 95%, a satisfiactorily high rate for such a long-term follow-up study. I am interested in conducting a similar study, a restrospective cohort study of leprosy patients in Japan. However, because of problems of hospital records, death certificates, etc., I am by no means optimistic about the feasibility of conducting such a study in Japan.

So far, I have discussed primarily the retrospective cohort study, because this is the kind of study where the strengths and weaknesses of various record systems in the two countries become apparent.

For case-control studies, I do not see much difference in record resources between the United States and Japan. Three years ago, we began a case-control study of breast cancer to investigate the etiological role of diet and exogenous estrogens among three populations who are at different levels of risk for breast cancer, i.e., Japanese in Hawaii, Caucasians in Hawaii, and Japanese in Japan (*5*). Except for minor differences, we have similar environments to conduct this project in Hawaii and Japan.

One of the major practical problems that we face in Japan is the verification of drug history. After cases and controls have been interviewed regarding their past intake or injection of hormones, we have tried to verify the statements of subjects by checking against medical records. However, this is a very difficult task, particularly when drugs were taken in the distant past, because of problems of medical record systems as mentioned above. In Hawaii, we face a problem of selection of neighborhood controls. We decided to select neighborhood controls in addition to conventional hospital controls because neighborhood controls are probably a better comparison group in terms of socioeconomic status and the fact that they are basically free of any disease. In Japan, the voter's list is being used and selection of neighborhood controls is not a problem. Neither voter's list nor census records are available in Hawaii, so that selection of neighborhood controls is done by using a cross-reference telephone directory and by door-to-door contact in neighborhoods, which, of course, is a very painstaking job.

This concludes my presentation of population registries and other record resources for epidemiologic cancer research studies in the United States and Japan. As I stated, we do not see much difference in usefulness of various records for the descriptive type of cancer research. However, for the analytic type of study, a retrospective cohort study in particular, we face clear strengths and weaknesses of various records systems in the United States and Japan.

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